

820 Jorie Blvd Oak Brook, IL 60523 TEL 1-630-571-2670 FAX 1-630-571-7837 RSNA.org



RSNA Press Release

Imaging Locates Kidney Lesions in Children with Tuberous **Sclerosis**

Released: October 29, 2002

Media Contacts:

Maureen Morley Heather Babiar (630) 590-7754 (630) 590-7738 mmorley@rsna.org hbabiar@rsna.org

OAK BROOK, Ill.—Children with the genetic disorder tuberous sclerosis complex (TSC) should be screened for kidney lesions beginning at age 10, according to a study appearing in the November issue of the journal *Radiology*.

TSC is a genetic condition characterized by benign tumors in the brain, eyes, heart, kidneys, lungs and skin, as well as behavioral disorders, developmental disabilities, kidney problems, seizures and skin abnormalities. Kidney lesions may lead to renal failure or severe bleeding, the leading cause of death in adults with TSC. Imaging can identify large lesions for embolization, a treatment that blocks blood flow to the lesion in an effort to prevent hemorrhage from the lesions.

"Families of patients with TSC need to know that angiomyolipomas occur in the majority of TSC patients and that these lesions can cause significant problems," said Lane F. Donnelly, M.D., senior author of the study out of Cincinnati Children's Hospital Medical Center (CCHMC).

In the United States, as many as 40,000 people are estimated to have TSC. Because of the wide range in the severity of symptoms, some people remain undiagnosed.

The study found that both angiomyolipomas, which are benign growths consisting of fatty tissue and muscle cells, and cysts commonly occur in children with TSC, and that the size and number escalate with increasing age. Angiomyolipomas are more common and abundant than cysts, and, when present, are often too numerous to count.

"The children [in the study] most commonly began developing angiomyolipomas when they were nine or 10 years old. Consequently, patients should begin routine screening at age 10 years," said Dr. Donnelly, Radiologist-in-Chief at CCHMC and professor of radiology and pediatrics at the University of Cincinnati, College of Medicine.

The researchers reviewed renal imaging findings and changes over time for 59 patients with TSC to gain a better understanding of the age when children first develop cysts and angiomyolipomas and to evaluate growth patterns over time. These findings were assessed

to recommend an age to begin imaging surveillance. The subjects had a mean age of 11.4 years and were screened with ultrasound, computed tomography (CT) and magnetic resonance imaging (MRI).

"Ultrasound screening is well suited to young children because it uses no radiation and is relatively inexpensive compared to other imaging techniques," Dr. Donnelly explained. "As the condition progresses, CT or MRI may be better at defining lesion size and anatomic location in the kidneys."

Specifically, the researchers found that 80 percent of the patients with TSC had angiomyolipomas, while renal cysts occurred in 47 percent of the patients. Additionally, angiomyolipomas were identified in both kidneys in 89 percent of the patients, while cysts occurred in both kidneys with less frequency (61 percent).

To minimize the risk of future complications, Dr. Donnelly recommends that children with TSC obtain a screening scan every other year beginning at age 10.

###

Radiology is a monthly scientific journal devoted to clinical radiology and allied sciences. The journal is edited by Anthony V. Proto, M.D., School of Medicine, Virginia Commonwealth University, Richmond, Virginia. Radiology is owned and published by the Radiological Society of North America Inc. (http://radiology.rsna.org)

The Radiological Society of North America (RSNA) is an association of more than 33,000 radiologists, radiation oncologists and physicists in medicine dedicated to education and research in the science of radiology. The Society's headquarters are located at 820 Jorie Boulevard, Oak Brook, Ill. 60523-2251. (http://www.rsna.org)

"Tuberous Sclerosis Complex: Renal Imaging Findings." Collaborating with Dr. Donnelly on this study were Keith A. Casper, M.S., Bin Chen, Ph.D., and John J. Bissler, M.D., from Children's Hospital Medical Center in Cincinnati.